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ABSTRACT

Counseling approaches for parents of young retarded children are reviewed. Guidelines are suggested for helping parents as they proceed through stages of protective denial (in which they need clear information about retardation), expectations of a cure (in which their attempts to further the child's development must be realistically balanced), verbalization without actual feeling, a period of mourning (in which they acknowledge the difference between the child they wished for and do not have), anger, and the final stage of coming to terms with the tragedy and using their energies positively. Counseling goals are seen to include giving parents initial support, encouraging realistic expectations, and providing specific child rearing methods which take into account their own needs and the needs of their other children. (CL)

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"Life Insurance" for Parents of Retarded Children Adolescents and Adults: Short and Long Term Parent Counseling Techniques

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Paper presented at the 54th Annual International Convention of the Council for Exceptional Children in Chicago, Illinois on Thursday, April 8, 1976.

by Nanette L. Doernberg, Ph.D.

Good afternoon ladies and gentlemen. As the titles of Dr. Wagner's and my papers suggest, we plan to focus on the need to change and to modify parent counseling techniques in a way that parallels the changing needs of the retarded child and his family. Our basic premise is that it is essential that professionals recognize the emotional evolution of the family which has a retarded child in order to offer maximum service to families.

As any good researcher knows, the first thing one must do is to define one's terms. In these papers, we use the American Association on Mental Deficiency's definition of retardation; mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period. It should be emphasized that there is no reference to etiology nor to prognosis. The individual is identified as retarded at the time at which he is being evaluated. By "significantly subaverage" it is meant that the individual has an I.Q. at least two standard deviations below the norm. This represents, on the Stanford-Binet and W.I.S.C., I.Q.'s of 68 and 70 or below. The developmental

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period is defined as up to 18 years of age. The manual emphasizes that a low I.Q. in itself is not a sufficient criterion to establish a diagnosis of retardation and that the level of adaptive behavior must be considered.

The emphasis in this paper will be on parent counseling for families of young retarded children, from birth to early elementary age.

Having defined the population we are discussing, I would like to define myself a little more clearly. I am a licensed Psychologist, the Director of a diagnostic and evaluation service that is part of a specialty clinic in the Department of Pediatrics at the Albert Einstein College of Medicine. My particular part of the clinic offers extended evaluation and diagnosis and short-term treatment to children under seven (in fact, most of them are under five) and their parents when diagnosis is a puzzle and/or when there are serious behavior problems which make it impossible to evaluate the child properly.

Having defined our population and myself, I would like now to state my bias and acknowledge that it is the fundamental concept on which our counseling is offered. I believe that the parents are just as important as is the child. A direct corollary of this is that in my opinion, parents of children with developmental difficulties are entitled to and deserve counseling, support and guidance. Further, I believe that the other siblings in the family are just as important as is the retarded child. I really see the

family relationship in almost algebraic terms; in other words, if there are three children in the family and one is retarded and there are two parents, I see the retarded child as one fifth of the family. This point of view has very direct and significant implications for the type of counseling which is offered.

Before I started to write this paper I did a highly selective review of the literature. The literature which I reviewed in this case was the program for this conference in Chicago. There is no question that there is an awareness of families of handicapped children in CEC's orientation. There has been a shift in this direction over the years and it is all to the good. Most of the parent programs approach the parents with the view of helping them help the child. This is indeed a valuable goal but perhaps a different way of looking at the family will make that goal and others more possible to achieve. I have been working with parents of children with developmental deviation for many, many years and it is my conviction that they would like to be seen as equal in importance to their children no matter how much they want to help their children. This may sound like an insignificant shift in emphasis, but I believe that it is fundamental.

When parents bring their child to the Early Childhood Center they are confused, anxious, and unhappy. They know that something is different about about the child and this awareness got them to the Clinic in the first place. At the point of entry, it is usually the mother that comes to the Clinic with her child, often directly

in opposition to the child's father's wishes and all too frequently despite the pediatrician's statement that there is nothing wrong with the child and will outgrow "it", whatever "it" is. During the process of diagnosis, parents are still able to hope that all will be well and that whatever is different about their child will be fixed or outgrown. As the evaluation is completed and the diagnosis of retardation is established, the immediate reaction of almost all parents is denial. This denial is natural in the face of information which delivers a stunning blow to the parents' ego. One of their major life efforts, their child, has been tried and found wanting as compared with other children.

This is one of the many points at which parents and professionals have a hard time communicating.

In addition to protective denial there is a matter of vocabulary. The professional who has made the diagnosis of retardation is basing his judgment on his understanding of what the term means. It is unreasonable to expect parents to use these words as we do. Most people think of mentally retarded children as stigmatized, non-functioning, non-verbal, non-toilet trained and grunting. They are unaware that there are degrees of retardation. They "know" about only severe and profound retardation. They believe that retarded people cannot learn and one of their major bases for rejecting the diagnosis of retardation is their quite accurate perception that their child has made progress and, indeed, can and has been learning. That is considered by them proof-positive that the diagnosis must be

incorrect. They do not believe that they have ever seen retarded people working in the community or functioning as mothers or fathers in a family. They do not truly know what the diagnosis means. At this time, they need a great deal of straight information as well as a great deal of support.

There are other problems in the concept of mental retardation for the parents of a young retarded child. Many of them have heard other kinds of diagnostic labels which they think exclude mental retardation, whereas we understand that mental retardation is a symptom which may be found in conjunction with emotional disturbance, brain injury, autism, and cerebral palsy, to name just a few. The sensitive counselor must recognize the need for time for the parents to even intellectually understand what mental retardation does and does not mean and that a child can be mentally retarded and something else too. The intellectual understanding may precede the ability to deal with the situation emotionally by a long, long time.

Stage two, after the initial denial of retardation and the statement that the child is only a "little slow", is an ability to recognize the youngster's current retarded status. Then parents often anticipate a significant change for the better in his rate and level of development. The question then is usually "Yes, he is that way now, but when will he grow out of it?" Closely related to this question is "How do we speed it up so that he will grow out of it sooner?" All of the worry at this stage is related to the immediate future. Problems of regular or special class placement are

voiced but not dealt with. Again, we are now talking about the parent who is now able to acknowledge verbally that his child is retarded, but who is still looking for magic solutions so that the prognosis will be for normal development.

It is particularly difficult for the parent when the child has made good progress and that, as a result of a treatment intervention, parents and professionals agree that progress has been made. Parents are then in a real double-bind. By this I mean that they have been encouraged and helped to understand their youngster's level of ability and to interact with him in a way that is most effective for the child and for them. By so doing, in the vast majority of cases they have truly helped the child function better. At the same time, this additional ability and competence which they develop as a result of our counseling leads them even more to believe that all things are possible.

We must then recognize that, while we are helping parents understand their children better and deal with them better, we are at the same time playing into their perfectly normal fantasy that if they do it all right the child will be all right. It is important to work through this with the parents in a way that does not discourage them from continuing to do what they can to enhance the youngster's behavior while still not being cruelly carried away by wishes that cannot come true. This delicate balance of encouraging growth and development in the child and family while at the same time encouraging reality-testing on the part of the family is one that is in a constant shift and change.

After a while, parents get to a point where they can <u>say</u> that they realize their child is retarded and that he probably will never be normal. It is important to realize that although they say it, they may not feel it. They may be saying it because they have learned that it is the correct thing to say. They may be saying it almost to test out their ability to endure the pain. They may be able to say it in the supportive circumstances of being in a parent group or in a professional's office whereas they may not be able to maintain this degree of reality-orientation outside of this enironment which is sheltered and safe and supportive for them. There is a great deal of normal slippage in the real emotional and intellectual grasp of this concept. It is particularly difficult for the parents of a young child because they can keep him out of competitive sight. In other words, they are able to keep the child close to them and away from other children his age, the presence of whom would make comparison inevitable. The younger the child, the more possible it is for parents to believe that there is not really a very big difference in his functioning.

Let us say that these stages of parental understanding have been helped to develop with sensitive counseling, and the parents truly have intellectually and emotionally come to terms and recognized the reality of their retarded child. I never use the term "accept" because I believe it is unrealistic. I think a realistic goal of counseling is to help families "acknowledge" retardation.

When the acknowledgment is true and deep, there is than a period of mourning. This mourning is for the child they wished for and do not have. This is well-documented in the literature but I think should be mentioned here because sometimes people who counsel parents are not aware that this is what is taking place. It is normal and it is healthy because it is a necessary part of coming to terms with reality. Until the parents can really give up the child they wished for, the normal, well-functioning child, the cannot deal with the child they have.

When this mourning period is passed, it is possible for the parents to turn their emotional energies in other directions. The first question after acknowleding the situation is usually "Why?" In some ways, this seems to be a flash-back to some of the magic and underneath the "Why?" is usually the hope that if we understand "Why?" we can fix it. Par of the reason for the "Why" is the universal feeling of guilt and the wish for absolution from this guilt. Parents want most desperately to know that they are not responsible for the situation. It creates an enormous additional amount of anxiety when we must truthfully tell families that in 85% or more cases we are unable to pinpoint the cause of the retardation. At this point again it is necessary to explain that it is a symptom which has many causes.

Although anger has been underlying the entire process of coming to terms with retardation this is the point at which it erupts most forcefully. Now the parents have understood that their child is

handicapped. The professionals have made a diagnosis. The diagnosis has been made but a cause has not been specified and a cure has not been offered. It is not hard to understand why parents find this unacceptable. They have gone to the powerful professional. They have given him or her their child to be helped. The child may have been helped but essentially, the parents are still stuck with the problem. They are angry at the doctors, although in most cases they are afraid to surface and express their anger. Sometimes it turns parents against each other.

While recognizing parental anger, it is vital to recognize that the doctors and other professionals are also angry. We are angry at the inadequacy of our knowledge, at the limitations of the "State of the Art". We all come into this field as nurturers and here we are dealing with a problem we cannot solve, either for the child or for the parents. We tend to be, although we rarely acknowledge it, angry at the child we cannot help and angry at the parents who want us to help so much when we cannot help enough. I am not suggesting that anger is our only feeling. I am suggesting that it is also there in us. It is important to help the parents recognize this anger on everyone's part, including our own. This is the point at which acknowledging our own regrets at the inadequacy of our knowledge is most useful to parents. It supports them by first recognizing their feelings; second, legitimitizing them; and third, sharing them by expressing similar feelings of our own. One of the most painful aspects of being the parents of a retarded child

is feeling outside of the human condition. Isolation and loneliness accompany the diagnosis. If the professionals involved can share with the parents their own feelings which are in many ways similar, although not identical, it enables the parent to see the professional as a counselor who emphathizes rathen than "teaches".

It is at this point that counseling can be most helpful to the family by helping the parent understand the needs of the entire family unit and with particular emphasis on the parents' needs and those of the normal siblings. The presence of a retarded child in the family really dislocates the family ecology. Because of factors that are too complex to detail here, but which include guilt and anger, one of the most common reactions after acknowledgment of diagnosis is massive parental effort directed toward the care and improvement of the retarded child. This seems to still go back again to an earlier stage and it will keep recurring. The earlier stage is that if enough effort is put into it, the situation can be remedied.

A good counselor will recognize that this is an underlying feeling and will encourage parents to accept the reality of their own importance and that of their normal siblings. Because so much parent counseling is geared toward helping the special child, we implicitly say to the parent that if they do less than everything for their special child they are failures as parents. I think we should be saying to them that, yes, they must acknowledge the needs of their special child but again, as I said at the beginning of my paper, I think it is equally important for them to acknowledge their

own needs and those of their normal children. The authority to permit themselves to feel this way must often come from the person who is counseling them. We must beware that we do not positively reinforce martyrdom which serves neither child nor family well.

After the many hours, days, weeks and months of painful imbalance, let us assume that the family has arrived at the point where the parents consistently recognize the retardation, and where they are able to consistently acknowledge it to themselves and to the people who have been counseling them. The next step is helping them deal with their immediate outside world, starting with the normal siblings and the extended family. We have worked with hundreds of parents who have come to the point just mentioned but who continue to shield their child from public view and who are unable to explain to their families or even to their older normal children what the problem is. Often, when they tentatively try, they are confronted with emphatic and seductive denial, accompanied by stories of other "much worse" children who are now psychologists or the heads of large corporations. When this happens, because they want so much to believe it, they are often lured away from their painfully gained new knowledge and regress to more comfortable denial. They really are not completely convinced themselves and therefore cannot convince others, especially since no one really wants to believe it. This cannot be rushed but must be recognized. Sometimes it helps to give parents actual words that they can speak to their own parents or to their neighbors or to the man in the

supermarket. Sometimes it helps to role-play. It always helps to acknowledge the painfulness of telling others about one's child with a severe problem. It does not help to minimize the enormity of the agony and the consistent embarrassment and feelings of inadequacy which accompany this gradual exposure to a gradual exposure to a less than sympathetic world.

Optimally, the next step is that the parents will have now dealt with the problems themselves, within their family, and within the neighborhood. They will have come to terms with their tragedy and will have begun to use their energies in ways that are positive for them and for their children. Many then find it very useful at this point to join parent organizations which work toward the help not only of their own child but of all children. In such an organization, they will find companionship and a reduced feeling of isolation. They may also find that something that has been perceived only as a terrible tragedy and waste can now offer some positive value in their lives, although the pain will always be there. In the beginning, at the point of recognition, counseling must be personal and individual. As adaptation grows, parents groups fill the need in a different way. The need is not static. The response to it must not be static.

In summary, what are my goals for counseling parents of young retarded children? One is, initially, to support them. They need it. A second is to gradually help them develop an understanding of the situation. It must be gradual and it will not be steady

progress but it will be forward two steps and backward one, sometimes backward two. A third is a recognition of appropriate expectations for their child, and most important, for themselves, not to have them expect to be all things to all people or even all things to their retarded child. Another is to learn specific child-rearing approaches suitable for these expectations which take into consideration the needs of the child and their own needs. We try to increase their competence and sense of dignity by really working together with them in increasing their knowledge about their child and how to deal with him, and indeed increasing their knowledge of the entire field, which gives them feelings of strength rather than of helplessness. We help them develop a frame of reference, an armature on which they can build future information and experience rather than have every new thing that comes up come as a total and unrelated surprise.

We help them deal with the present while recognizing that their concern is not only for the present but for the future. We feel that the future can only be helped by dealing with the present as well as possible. It is our goal with the parents of young children to help them come to terms with the present and help them garner the strength and understanding to settle in for the long pull. We know, and they often begin to perceive, that the situation while the child is small, young and usually still cute is different from what it will be in 15 or 20 years. The counselors of parents of young retarded children must acknowledge these forebodings and deal with them as real, present worries about a future problem.

The counselor of parents of adolescents and adults who are retarded are dealing with these forebodings come true. Dr. Wagner will address her paper to this topic.